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WHAT YOUR PATIENT IS THINKING

Help me trust you after my misdiagnosis

Sarah Clark shares what it is like to experience a misdiagnosis and how health professionals can support someone who has been misdiagnosed

Sarah Clark

Debilitating daily life

For more than 12 years I lived with undiagnosed chronic pain, spinal problems, pelvic floor dysfunction, gastrointestinal issues, bladder problems, bleeding tendency, and easy scarring, among other symptoms. I was exhausted. Living with all these problems in combination made my daily life debilitating and challenging on a practical level. But even more difficult was not being believed about my physical problems by health professionals.

While trying to find answers about my physical symptoms I had accrued a collection of psychiatric diagnoses, including emotionally unstable personality disorder and neurotic depression. These stigmatising descriptors meant it was difficult to have my physical symptoms taken seriously, or even believed at all. I felt like the labels made my doctors invalidate any of my physical symptoms. They continually accredited the symptoms to my psychiatric labels and my history of sexual abuse.

Facing a misdiagnosis

As I had received several psychiatric diagnoses, the pain team wouldn't help with my physical pain. The mental health team told me I had health anxiety. No one could appreciate the amount of physical pain I was in, or how it affected my daily life. I felt my credibility with health professionals being increasingly undermined as most of my doctors saw mental health problems as the only ones I had.

Over many years, my undiagnosed physical problems and mental health diagnoses had a devastating impact on me. I simply couldn't stand the physical pain and bladder and bowel complications, and felt like my physical health problems were being invalidated. As my physical health deteriorated, the exhaustion from fighting to be believed and to get appropriate help made me feel like my life was too difficult. This even led to suicide attempts.

How to rebuild the trust

Eventually, a magnetic imaging scan showed features suggestive of hypermobility. This led to a diagnosis of hypermobile Ehlers-Danlos syndrome, a rare genetic disorder of the connective tissue. It was a huge relief. I finally had some answers, but I also felt I had wasted years of my life trying to convince health professionals of my physical symptoms.

Rebuilding trust with patients who have been previously misdiagnosed requires time, compassion, and empathy. Ensure you are really listening to

patients. Consider what it must be like to live with the symptoms they are describing. Be open and honest if you feel you might not have the relevant knowledge or experience to help them. Help us feel heard and respected by acknowledging our perseverance in getting a diagnosis.

Finally getting answers

The usefulness of getting a diagnosis for Ehlers-Danlos syndrome is commonly questioned as there is no cure. However, with better management of physical symptoms and support, my life has dramatically improved just this past year. I have got back some aspects of my health and wellbeing that I thought I had lost forever. I am even back at university studying for a masters degree in neuropsychology. This simply would not have happened if I hadn't fought so hard for a correct diagnosis.

What you need to know

- Listen to your patient's concerns and explore their ideas about diagnosis before deciding on your own
- Compassion and empathy are even more important when a patient may appear defensive; try to consider their previous negative experience of healthcare
- Being honest and transparent with patients can help rebuild the trust

Education in practice

- How can you help someone who has experienced a misdiagnosis feel that you have listened and heard their concerns?
- What support could you give someone who has lost their trust in the health service?
- If you have been involved in an error that has affected a patient, how might you have improved your communication with them about what happened?

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